Submission No 7

INQUIRY INTO 2018 REVIEW OF THE DUST DISEASES SCHEME

Organisation: Bernie Banton Foundation

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BANTON
FOUNDATION

Asbestos disease… takes your breath away!®

02 November 2018

The Committee
Standing Committee on Law and Justice
Parliament of New South Wales
Parliament House
Macquarie Street
Sydney NSW 2000

By email: lawandjustice@parliament.nsw.gov.au

Dear Committee,

We are thankful for the opportunity to provide a submission to the Committee's 2018 Review of the Dust Diseases Scheme.

Please do not hesitate to contact myself or the Bernie Banton Foundation's CEO and Founder, Karen Banton, if you feel we can assist the Committee with further input.

Sincerely,

Rod Smith

Awareness and Support Co-ordinator
Bernie Banton Foundation
Dust Diseases Board Member
Member of the Expert Advisory Group for the Australian Mesothelioma Registry

ABOUT THE BERNIE BANTON FOUNDATION

The Bernie Banton Foundation is a New South Wales based and registered, mesothelioma and asbestos related support organisation.

We are an apolitical, not for profit organisation with authority to operate in all Australian states and territories.

The Foundation's Mesothelioma and Asbestos Related Support (**MARS**upport) Network is physically active throughout NSW and the ACT offering peer-based support and information, and referral and advocating services to those who have been diagnosed with mesothelioma cancer or another asbestos related disease (ARD), and to their carers and immediate family members, as well as those bereaved. Our Freecall Asbestos Disease Support Helpline, available Australia-wide, is open 24 hours a day, 7 days a week offering peer-based support and information from people who have, importantly, lived the mesothelioma or other asbestos diseases journey. We are also active online via our comprehensive website, online support groups and social media based information platforms.

Currently the Foundation's **MARS**upport Network has in excess of 400 sufferers, carers and family members on our NSW and Dust Diseases Care related support database, with the vast majority being directly, or indirectly connected with Dust Diseases Care.

2018 Review of the Dust Diseases Scheme – November 2018

Since writing and submitting a submission to the Committee for the First Review of the **Dust Diseases Scheme** in April 2017, and appearing to give evidence before the Committee in July 2017, much has changed regarding the operations and workings of **Dust Diseases Care** (**DDC**).

From a service driven, people focused organisation perspective, dealing daily with **Dust Diseases Care** clients and often advocating on the client's behalf to **DDC**, we have experienced and noticed a raft of changes implemented, and a continuance of historical problems yet to be re-worked or overcome.

As with the First Review submission, I will endeavour to give the Committee both an honest and factual assessment of **Dust Diseases Care** and the Dust Diseases Scheme as we experience it.

SERVICE PROVISION

Since writing the submission for the First Review I am pleased to see much that came out of the First Review has been taken on board by **DDC** and implemented.

CUSTOMER LIAISON TEAM

In September 2017 a Customer Liaison Team was started, this meant new clients are allocated their own direct contact within **DDC**, rather than be faced with potentially speaking with a dozen different people within the compensation and service delivery spectrum of **DDC**. This is a great initiative that has been received kindly by new clients – unfortunately, it is not offered to clients registered prior to the September 2017 start up date.

Expanding the team to satisfy future demand will be key to the Customer Liaison Team members being able to dedicate the time that is so necessary, when dealing with people who are invariably physically or emotionally fragile, or both. As the demands grow, team leaders and management will need to be able to recognise the stresses placed on staff when demand necessitates they can no longer give caring and adequate service, and are constantly under the pump.

From my own experience, speaking with a client for an hour or more is not unusual – how do you rush through or simply hang up on someone who desperately needs your help and guidance? This is particularly so when figures show a huge percentage of clients have no way of communicating, other than by the age old method of speaking on the phone, or writing a letter.

This is backed up by the number of times we are told how 'good', 'wonderful' or 'lovely' a client's **DDC** Customer Liaison Officer is!

LONG TERM CLIENTS REGISTERED BEFORE SEPTEMBER 2017

As was stated in the First Review it is obvious to us a lack of communication between the **DDC** and those registered with the **DDA** (and vice versa) is the main reason for the vast majority of any problems that arise. This would seem to be particularly the case for those not covered by a Customer Liaison Officer.

Unfortunately those registered before September 2017 do not have the luxury of the Customer Liaison Team. These 'hidden majority' are often totally out of the loop and have no idea of the services they could be entitled to. This is highlighted where a client who may have been registered with a low level diagnosis such as pleural plaques (which are not compensable), but over the years has been diagnosed with a more severe dust disease or progressed into a situation where greater services can be provided.

When the Foundation is alerted to a problem, and advocates on behalf of those concerned to Dust Diseases Care, invariably the problem is dealt with expeditiously by the **DDC** – we couldn't be happier with reaction times and the attitude of **DDC** staff from the top down, when an issue becomes apparent, and we can contact the right person to talk to about it.

REGISTRATION APPLICATION PROCESS

The **Dust Diseases Authority** application process has had a major overhaul, with the process being streamlined and is more user-friendly. Applicants can now register online, over the phone (with the help of a Customer Liaison Officer) or the traditional pen to paper method. This has been a major change that should be applauded.

Whilst the application process may have had a major overhaul, there are still hold ups to the system that do not seem to have ready answers. From an outsider's viewpoint, the major holdup is still the **DDA** accessing medical records from all sectors of the medical fraternity. Another point of concern beyond the control of the **DDA** is, frighteningly, a sufferer is often given a diagnosis that is vague or outright nonsensical, with sufferers often told they have, for example: 'Asbestos On The Lung' – which is not a diagnosis at all!

Overall though, it would seem the application process is working well, not withstanding the constraints mentioned above.

COMMUNICATIONS

The major complaint the Foundation receives from clients concerning DDC is not being able to contact anyone or receive a reply to a message left or an email sent.

As good as many of the members in the **DDC** team are, they become ineffectual if they cannot be directly contacted by phone. In February 2018 icare installed a new Internet-based phone system that frankly is abysmal, often sending clients into a never-ending loop of a recorded message. If you did get to leave a message, there was no confidence that it would be heard and hence returned.

This situation seems to have been somewhat corrected, if you have a known direct contact number to a particular Team member.

Unfortunately, clients and others are contacting the Foundation as they have found when trying to contact the **DDC** using the listed general public contact phone number (once you can find the number on the new icare website) it is difficult, if not impossible to contact an actual person at **DDC** without hanging on for an unacceptable amount of time.

I recently put myself through the process of using the general number to experience what others are experiencing; I waited for 34 minutes listening to a recording without the option of leaving a message.

I can understand why often elderly, frail people in ill health won’t hang on, and those with busy lives don’t!

I can only assume this situation has occurred due to system and staff overload, but I have no knowledge of internal figures, or of what staff are actually experiencing.

What I do know, in this day and age it is unacceptable to be on hold for over half an hour without being given an option to leave a message.

My fear is the **DDC** (**icare**) overall operating system (whether by design or default) like so many others, is being geared to the now IT savvy generation – emails, texting, etc. (anything bar actually talking to someone) rather than its’ client main demographic, which is the non-IT savvy generation in the late 70s and 80s.

Experience has shown the best way to deal with most clients in our’s and the **DDC’s** space is to talk with them and guide them through situations. Copious quantities of paperwork, or sending an email as an alternative to actually talking is not desirable, but seems to be a preferred option in this day and age where saving time, KPIs and meaningless buzz words and phrases seem to be a measure of success.

What is evident, an adequately staffed **DDC** Team prepared and able to talk with people instead of emailing, without time restraints being applied, is essential to a client receiving deserved service from **DDC**.

SLOW PAYMENTS

After ‘not being able to contact anyone’, the next biggest complaint we receive is the age old one of ‘waiting for payments’. This was a prevalent complaint we received during the days of the original **DDB**, and is still a consistent one now.

This would often seem to be brought about due to a lack of knowledge by the client of the necessary processes, or a ‘disconnect’ between a service provider and **DDC**. Often it only takes an explanation, simply knowing who to talk to, or what questions to ask to alleviate, or satisfy a problem.

When the Foundation is alerted to a problem, and advocates on behalf of those concerned to **Dust Diseases Care**, invariably the problem is dealt with expeditiously by the **DDC**.

CARERS

During the year **DDC** has engaged Carers NSW to partner in a limited Carers mentoring program, which involves eligible carers being given the opportunity to receive a set number of mentoring sessions. The Foundation has received zero feedback on this program to date, and look forward to future assessments of its worth.

Recommendations:

[1] The Customer Liaison Team be expanded to not only allow Team Members to spend ‘as much as is required’ time with clients, but also to allow all **DDC** clients to be allocated an individual Liaison Officer.

[2] Pro-active systems and processes be put in place to allow for clients registered prior to September 2017 being prioritised for contact, and to receive an allocated Customer Liaison Officer.

[3] Communications and staffing levels be increased, to allow for phone contact to be made in a reasonable time.

DUST DISEASES BOARD

The **Dust Diseases Board** was legislated to enable an independent process to award grants to further clinical or research work, or any other purpose relating to the prevention of **DDA** listed legislated dust diseases, and to aid stipulated dust disease support organisations to function and perform their vital support, awareness and patient related advocacy services.

It has become obvious the allocated funding the **DDB** has at its disposal, which has remained unchanged for many years, needs increasing to make it more relevant to today’s costs in conducting research and running support organisations.

This is something the vibrant Board, newly appointed 01 March 2018 will no doubt take to task with the **DDA**, the custodians of the Workers Compensation Dust Disease Fund.

Recommendation:

Legislation be amended to recognise the **DDB** as having a role as an expert advisory panel to **icare** and the **DDA**.

CONCLUSION

There is no doubt in my mind, there have been substantial positive changes take place since September 2015, when the service delivery side of the **DDB** was integrated into, and placed under the umbrella of Insurance and Care (**icare**) **dust diseases care**.

I fear though, there is a real danger these positive changes will be lost, as modern day society continues to forge ahead with almost constant change that is beyond the ability of the main demographic of DDC clients to comprehend, or come to terms with - as would appear to be happening with the NDIS and Aged Care.

The **DDC** management team will need to be aware of, and keep mindful of the fact that what works in other sectors of **icare**, such as **icare lifetime care** may not be appropriate for **DDC**.

All the strategies, purposes and visions, target outcomes, customer pillars, enablers and other modern day buzz words will mean little if the very people **Dust Diseases Care** is meant to care for, cannot relate to or understand the changes being instigated – or worse, cannot access them.

After nearly ninety years of the **DDB**, the first three years of **Dust Diseases Care** has outwardly gone well, the challenge is for it to continue on a tangible relevant upward spiral, and not to embrace change purely for the sake of change.

We need to ensure all the good of the **COMMERCIAL MIND** does not siphon the soul out of the **SOCIAL HEART**!